

Special Health Services (SHS)
Family Advisory Council (FAC) Meeting
January 11, 2020

Attendance:	
Guest Speakers	Sara Stolt (DHS COO); Julianne Horntvedt (DD Council Director)
Family Advisory Council Members	Moe Schroeder (phone), Victoria Johnson, Sarah Carlson, Joseph Liccini, Abbi Berg, Amber Cummings, and Jessica Howling Wolf
SHS Division Staff	Kimberly Hruby, Heather Kapella, Tina Feigitsch, Danielle Hoff, and Amy Burke
Welcome and Introductions	The Special Health Services (SHS) Division Director, Kim Hruby, provided a warm welcome and relayed appreciation for the time devoted for the Family Advisory Council (FAC) meeting and the commitment made by participants to assist the division in its work throughout the year. Introductions were made and new member, Jessica Howling Wolf, was welcomed.
Ice Breaker	Abbi Berg facilitated an Ice Breaker activity to start the meeting. Cell phone photos were described by FAC members, guests, and SHS staff.
Last Meeting Follow-Up and Approval of Minutes	<u>Review and follow-up items to be addressed from last meeting on September 14, 2019.</u> <ul style="list-style-type: none"> All recommended items have been in progress or completed. <u>Minutes and Recommendation/Review Summary from September 14, 2019</u> <ul style="list-style-type: none"> Sarah motioned to accept the minutes. Abbi seconded the motion. Motion unanimously carried to accept the meeting minutes as written.
Guest Presentation: Sara Stolt discussing changes in DHS with potential to impact SHS	Sara Stolt from the ND Department of Human Services provided an update regarding the county social service redesign. <ul style="list-style-type: none"> Background: Senate Bill 2124 moved 53 counties into 19 social service zones. Counties are now combined for service delivery. Expenses can be shifted more into programs and services. Citizens still go to their local county social service office. Process redesign will also be taking place. DHS does not need to wait until a determination has been made before beginning services. The ultimate goal is to be more efficient and more effective.

	<ul style="list-style-type: none"> • The process should also be made easier for the employee. • A culture change regarding “change being bad” is being tackled. • Over the next 6 months the zones will be putting together their operational plans. • Over the next 3 months, zone directors will be hired. • Sarah C. asked questions regarding Medicaid redesign: <ul style="list-style-type: none"> ◦ Medicaid eligibility redesign will start in March 2020. • Jessica spoke up regarding the inconsistency in notices: <ul style="list-style-type: none"> ◦ Systems automatically generate letters regarding eligibility. ◦ Sara indicated they are having some glitches with the implementation of the new SPACES system for eligibility. • Victoria works with Families United for Advocacy, which is more geared towards education. She indicated many families are calling stating they are being kicked off Medicaid due to income although income for families did not change. • Amy discussed the issues with Medicaid automatically choosing a primary care provider in the system. • Families can go to the county that is most convenience for them. However, they cannot flip-flop between counties. • Moe asked which Medicaid application families should be completing when applying for the Medicaid Buy-In because this is determined by net income instead of gross • Amber asked if the autism waiver has a separate application. Sara will check on this. • Sarah C. also brought up the education around Early Periodic Screening Diagnostic & Treatment (EPSDT) is severely lacking.
SHS Application Update (Tina & Danielle)	<ul style="list-style-type: none"> • Tina gave an overview regarding the change with application process and how this has now moved into the state office rather than being administered by the county. • Meeting the families in person and getting their story has been eye-opening for SHS staff. • Abbi emphasized that this was one of the hardest things for their family, so she appreciates the change to the state office administration.
Update on Mandated Reportable Conditions (Kim H.)	<p>Kim gave an update regarding the mandated reportable conditions.</p> <ul style="list-style-type: none"> • This mandate went into effect on 10/1/19. A webinar was held on 1/7/2020 to answer any questions regarding these changes. The conditions that SHS will be working with are: <ul style="list-style-type: none"> ◦ Visible congenital anomalies

	<ul style="list-style-type: none"> ○ Critical Congenital Heart Disease (CCHD) ○ Fetal Alcohol Syndrome (FAS) ○ Neonatal Abstinence Syndrome (NAS)
Newborn Screening Car Seat Sticker Project (Amy)	<p>Amy Burke gave an update regarding the projects within Newborn Screening, including the new welcome card and emergency sticker for cars eats. Feedback was requested from the council regarding suggested changes or modifications.</p> <ul style="list-style-type: none"> • Abbi recommended that although this is helpful, she did not feel like it should replace the phone call that occurs from SHS. • Amy will continue the phone calls but is hopeful that by seeing the welcome card in the mail they will be expecting her phone call. • Sarah C. will send Amy any additional comments before this project is finalized. • Joe recommended that the welcome letter might be more effective if sent through email instead of snail mail. The car seat sticker could also be sent as a fillable PDF since some have messy handwriting. • Amber pointed out that emergency workers would need to know to look for the car seat stickers. <ul style="list-style-type: none"> ○ Amy referenced that she has been working with the child passenger safety program to work with their emergency contacts. ○ Danielle mentioned that there might be a way to alert the medical professionals to look for the car seat sticker through the medical record.
DoH Surveys (Heather)	<ul style="list-style-type: none"> • A survey for the Title V MCH Needs Assessment was distributed to members fill out from our MCH Epidemiologist, Grace Njau. <ul style="list-style-type: none"> ○ This survey will help to identify perceived MCH priorities from our Family Advisory Council. • Information from Dawn Mayer with the Child Passenger Safety Program was not available for this meeting. <ul style="list-style-type: none"> ○ Dawn Mayer's contact information will be sent to meeting members.
Guest Presentation: Julianna Horntvedt discussing DD Council Opportunities for Families	<ul style="list-style-type: none"> • Julianne Horntvedt, Executive Director of the State Council on Developmental Disabilities, Department of Human Services, presented. <ul style="list-style-type: none"> ○ Information was shared regarding various scholarship opportunities available for families to attend training or conferences. Handouts regarding these opportunities were disseminated to the group.

Closing Remarks/ Wrap-Up and Reimbursement	Reimbursement Forms/Adjournment <ul style="list-style-type: none"> Forms were collected, and member information and updates were verified. Several members volunteered to attend the Medical Advisory Council (MAC) in May, which takes place in the morning before the next Family Advisory Council Meeting. <ul style="list-style-type: none"> Volunteers expressing interest in attending MAC: Sarah, Victoria, Joe, Jessica Jessica was willing to share her family story at the May 2020 meeting.
Upcoming SHS Family Advisory Council Meeting Dates for 2020	<ul style="list-style-type: none"> Confirmed—May 2, 2020 1:30 p.m. – 4:30 p.m. (following Medical Advisory) Confirmed—September 19, 2020 9:00 a.m. – 12:00 p.m.

SHS Family Advisory Council Recommendation/Review Summary

Meeting Date	Advice and Follow-Up	Action Taken
January 11, 2020	Send out a list of contact information, including SHS staff and guest speakers for follow-up by FAC members after the meeting	A list of contact information was sent to the FAC members on January 15, 2020.
	Send out contact information for Grace Njau, MCH Epidemiologist and Dawn Mayer, Child Passenger Safety Program.	Kim Hruby sent an email to FAC members with this information on January 27, 2020.
	The Newborn Screening welcome letter should not replace the follow-up phone call from a staff member.	Amy Burke assured the council that the welcome letter will be used as a communication tool, but not a replacement for the phone call.
	Consider sending the Newborn Screening Letter through email instead of standard mail.	This will be further explored as Long-term Follow-up is developed, as certain permissions might need to be obtained for email.
	The Newborn Screening Car Seat Sticker to indicate a special need may work better as a hanging item, such as a luggage tag.	Amy checked with the Child Passenger Safety Program, and they stated no items may be hanging from the child's car seat. Will continue with an adhesive product.
	The list of SHS covered medical conditions was requested	Kim Hruby emailed this list out to the council members,

	by the council, so they can share information about the Financial Coverage Program with others.	along with the link to the new website, on January 25, 2020.
	The Family Advisory Council stated that moving the meetings away from a Saturday would not work for majority of the members.	The SHS Division agreed to keep FAC and MAC meetings on Saturdays to assure representation from council members.